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CARING FOR CAREGIVERS

When someone begins their Hereditary Angioedema (HAE) journey, it's incredibly important to have at least one person close to them who can be by their side to provide care and support. The role of a caregiver in the life of someone with a HAE diagnosis is invaluable. These special individuals provide unwavering emotional support, ensuring their loved one never feels alone in their journey.

With dedication and compassion, caregivers assist with daily activities, offer practical help, and become advocates for their loved ones' medical needs. Their presence brings comfort, peace, and a sense of security to their loved ones, making a significant difference in their quality of life. The dedication and selflessness of caregivers are instrumental in empowering individuals with HAE to face their challenges with strength and resilience.

What is a caregiver?

A caregiver is anyone who is available at some point or all the time to provide support and assistance during your HAE journey. Here are some examples of individuals who might serve as a caregiver to someone with HAE:

- 1. FAMILY MEMBERS:** This includes spouses, parents, siblings, children, or other relatives who take on caregiving responsibilities.
- 2. FRIENDS AND NEIGHBORS:** Close friends or neighbors who are willing to provide support and help when needed.
- 3. ACADEMIC AND EXTRACURRICULAR RELATIONSHIPS:** School nurses, teachers, guidance counselors, coaches, college roommates, and dorm resident assistants (RA) are among those who might offer support and care to someone with HAE while they are at school or engaged in extracurricular activities.
- 4. SUPPORT GROUPS:** Regular meetings with other individuals with HAE, such as those sponsored by the US HAEA, build support networks that strengthen community engagement and friendships to help each other through challenging times.

What can I do as a caregiver to support my loved one with HAE?

As a caregiver, there are several ways that you can support your loved one with HAE:

EMOTIONAL SUPPORT: Ask your loved one what you can do to help them in their HAE journey. Be prepared to offer assistance during attacks or medication administration. Be a compassionate listener and provide a safe space for your loved one to express their feelings and concerns. Offer encouragement, empathy, and reassurance.

EDUCATION AND ADVOCACY: Educate yourself about HAE using available resources. Stay updated on the latest research, treatment options, and available resources. Serve as an advocate by accompanying your loved one to their medical appointments, taking notes, asking questions, and ensuring their concerns are addressed by healthcare professionals.

BUILD A SUPPORT NETWORK: Get involved in support networks by connecting your loved one with programs and services offered by the HAEA. These resources include webinars, newsletters and social media updates, support groups, printed resources, and individualized support for both patients and caregivers. The HAEA provides reliable information and opportunities to connect with others facing similar experiences through virtual and in-person events.

RAISE AWARENESS: Raise awareness about HAE. Educate those around you such as family, friends, medical professionals, decision makers, and your local community to foster understanding, support, and a sense of support for your loved one.

The HAEA offers support to community members who wish to create their own Do-It-Yourself (DIY) HAE Awareness event. Some examples include hosting a bake sale, awareness walk, or even decorating a float in a local parade!

COMMUNICATE OPENLY: Keep in mind that every individual's needs are unique. As a caregiver you need to communicate openly and honestly with your loved one, and adapt your support based on their needs. Working together as a team and seeking support from healthcare professionals and relevant organizations like the HAEA can greatly enhance the care and support you are able to provide as a caregiver.

Be Mindful of Your Own Health

Your wellbeing is just as important as your loved one's. Think of the expression "you can't pour from an empty cup." To provide the highest level of care for your loved one, you must be mentally, emotionally, and physically able. This is why it's important to remember to care for your own wellbeing as a caregiver. Keep these suggestions in mind to keep you mentally and physically fit as a caregiver:

1. **Communication is a two way street.** Keep communication with your loved one open and honest. Make sure they're comfortable confiding in you for what they need, but also know that you can communicate your feelings to them as well.
2. **Take time for yourself.** Caring for someone else isn't easy. It can be tiring both emotionally and physically and you need to make sure that you prioritize your happiness and wellbeing. This can be as simple as taking a short walk around your neighborhood, setting some time aside to read your favorite book, or listening to your favorite music.
3. **Build a community of support for yourself.** Caregiving is not a journey that is meant to be taken alone, both you and your loved one need a support system that you can lean on. Mental health professionals can offer invaluable support during this time. The HAEA offers monthly support groups that allow both patients and caregivers to discuss with others their own personal journeys.



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